



Cancer Control & Population Sciences

Resources for Studying Rare Cancers

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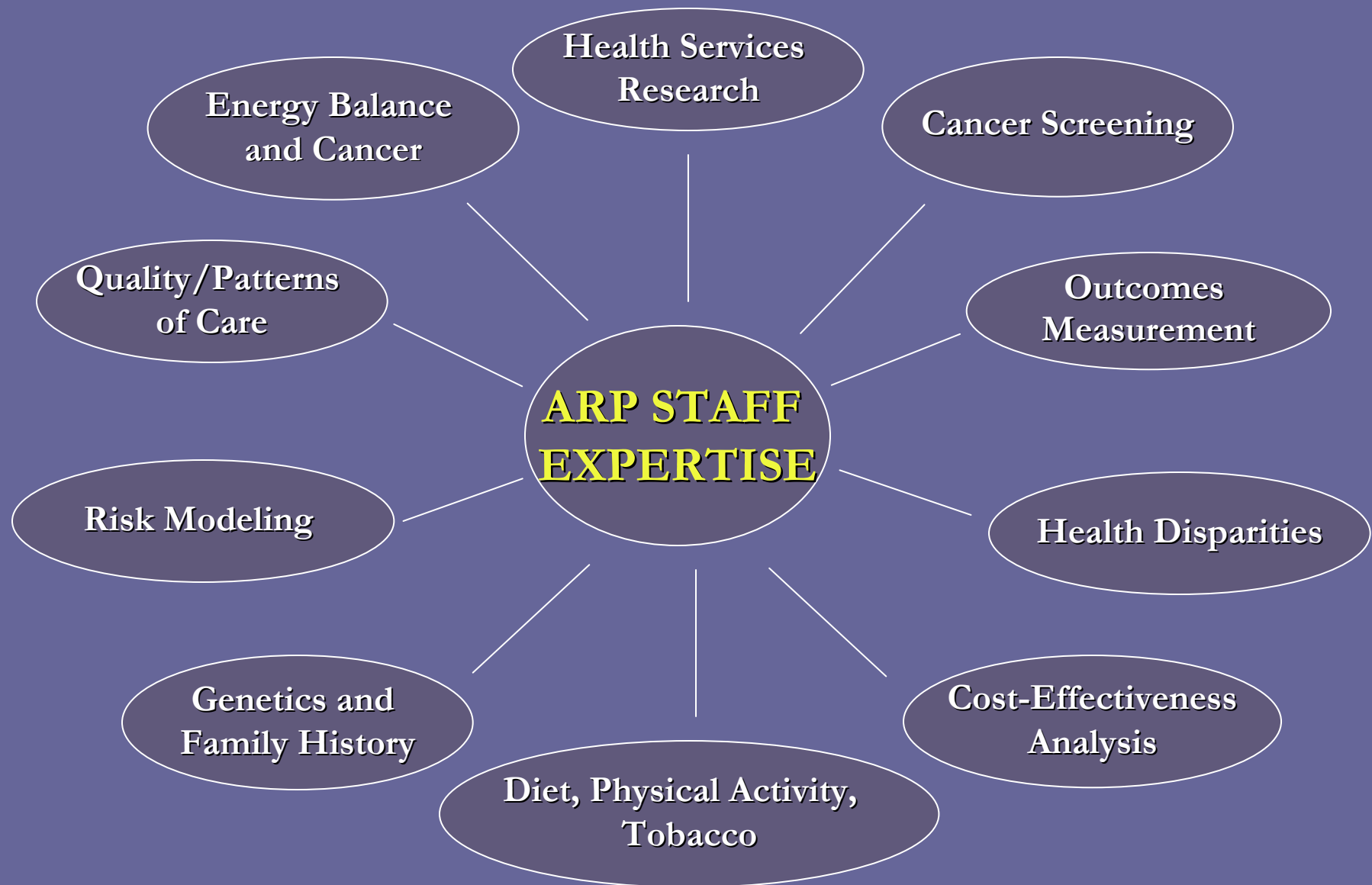
National Cancer Institute

**NCI Leadership Workshop
Understudied Rare Cancers
Boston, Massachusetts
September 12, 2005**



Applied Research Program: Mission

- Support the evaluation of patterns and trends in cancer-associated health behaviors, practices, genetic susceptibilities, health services, economics and outcomes.**
- Monitor and evaluate cancer control activities in general and specific populations in the United States**
- Determine the influence of these factors on patterns and trends in cancer incidence, morbidity, mortality, survival, cost and health related quality of life**

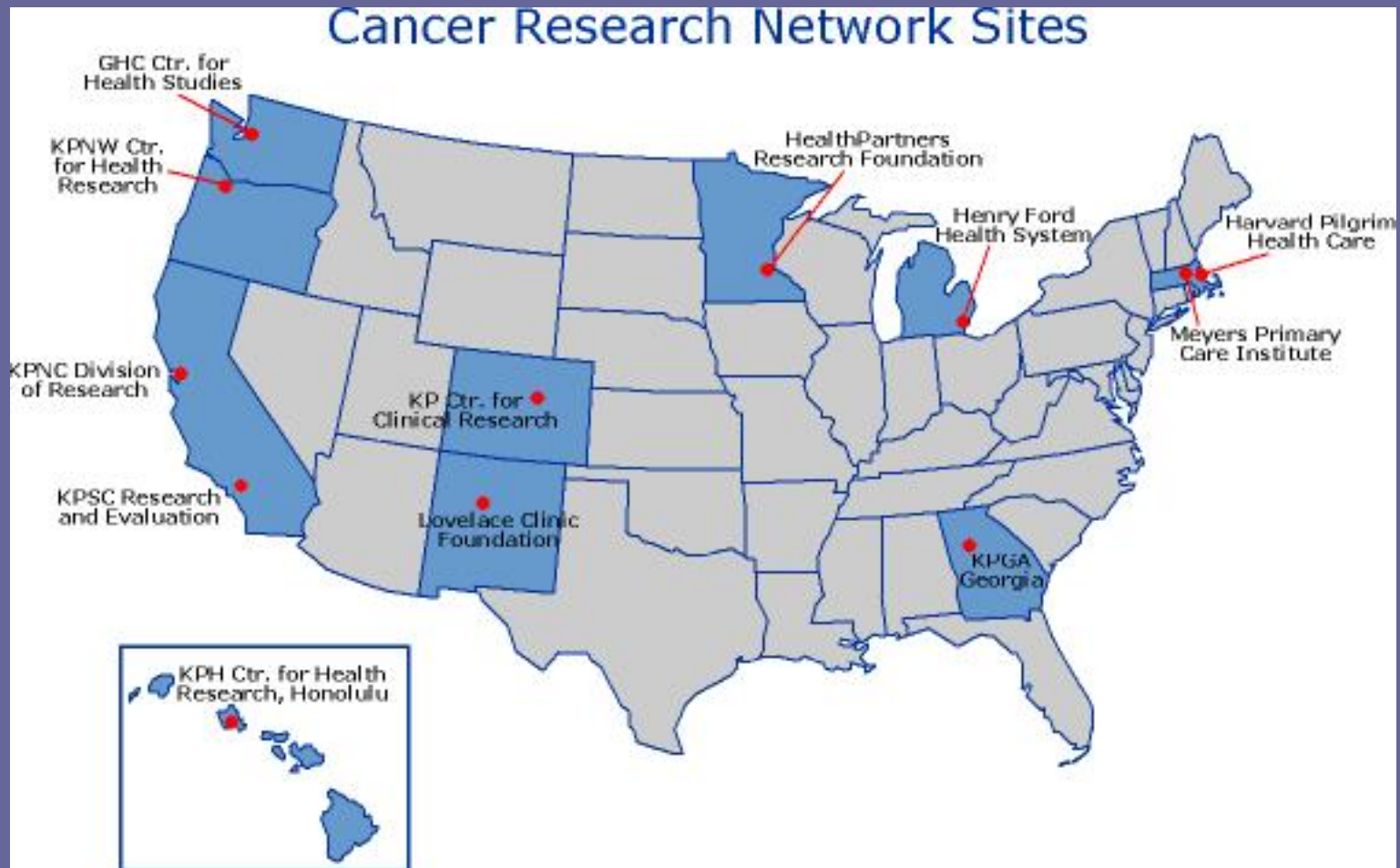


<http://appliedresearch.cancer.gov/about/staff/>

Applied Research Program: Rare Cancer Resources

- Breast Cancer Surveillance Consortium(BCSC)
 - DCIS and cancers in subgroups
- Cancer Research Network (CRN)
- SEER-Medicare

The HMO Cancer Research Network



CRN and Rare Cancers

Automated data sources and large, diverse populations enable myriad studies of less common cancers

- **Patterns of care**
- **Incidence trends**
- **Molecular epidemiology**
- **Survivorship**
- **Disparities**

CRN: Prevalence Rates for Select Rare Cancers

Cancer	# of Cases 1990-2002
Pancreas (all sub-sites)	7955
Multiple Myeloma	4294
Esophagus (all sub-sites)	3350
Liver	3225
Glioblastoma, NOS	2998
Cervical Adenocarcinoma, NOS	684

CRN: Multicenter Study of Pancreatic Cancer Etiology

Risk and molecular events leading to development of pancreatic cancer

- **Two CRN sites (GHC & KPNC); 2 more to be added**
- **Includes collaboration with EDRN to study serum markers**
- **Biospecimen collection (blood, tissue)**

CRN: Multiple Myeloma

Preliminary analysis of differences by race among multiple myeloma patients

Cohort N = 1695, DX'd 1993-1998

- 19% African American; 9% Hispanic**
- 70% of patients died within 5 years, regardless of race (unadjusted)**

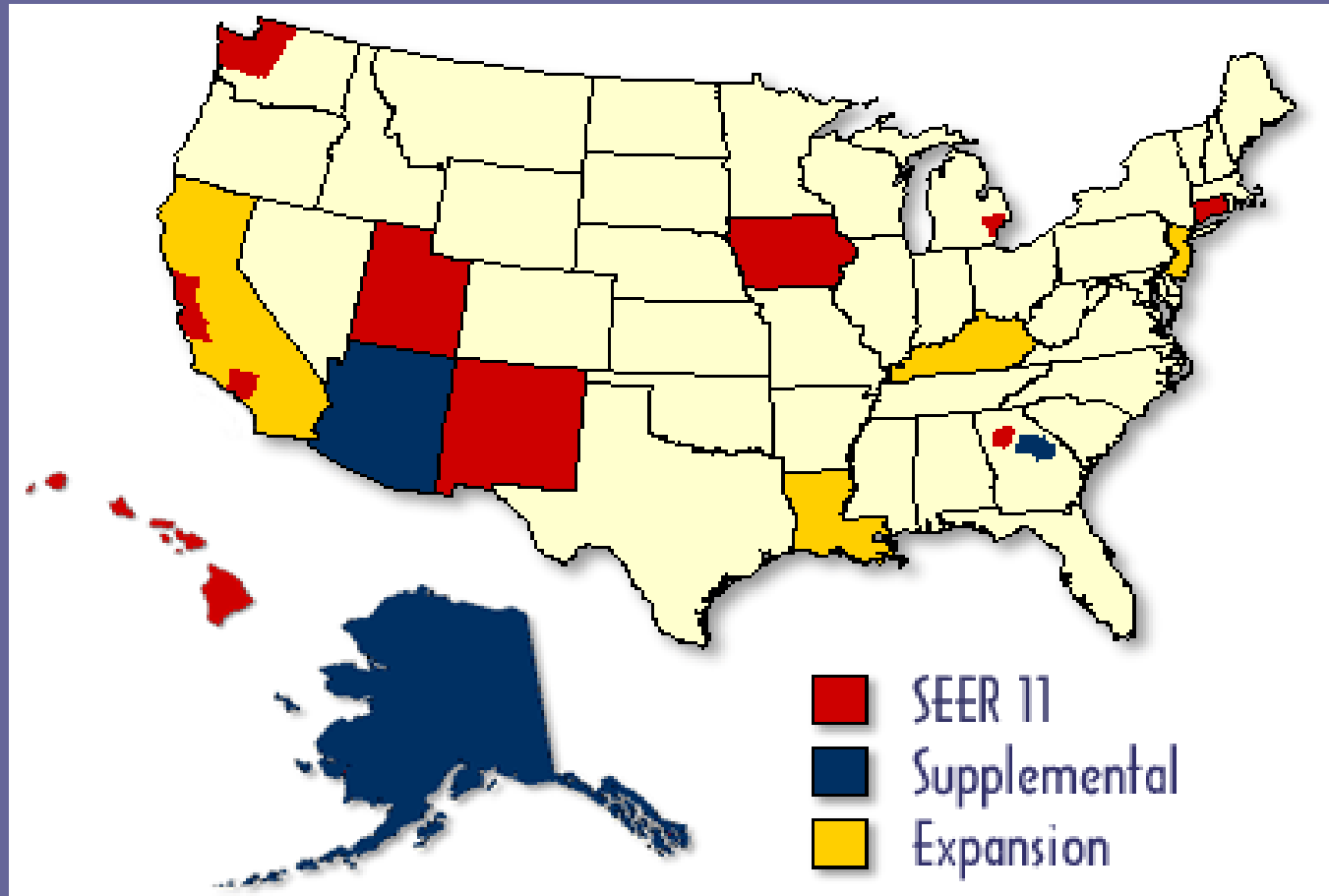
How to Work with CRN

- CRN is not a public-use database
- CRN is not a funding source
- Access to CRN is through collaborative research with CRN investigators
- External collaborations are initiated by submitting a short proposal to CRN
- Initial estimates of cancer cases, and related CRN data, e.g., healthcare and pharmaceutical utilization are available through the CRN Virtual Data Warehouse

SEER-Medicare

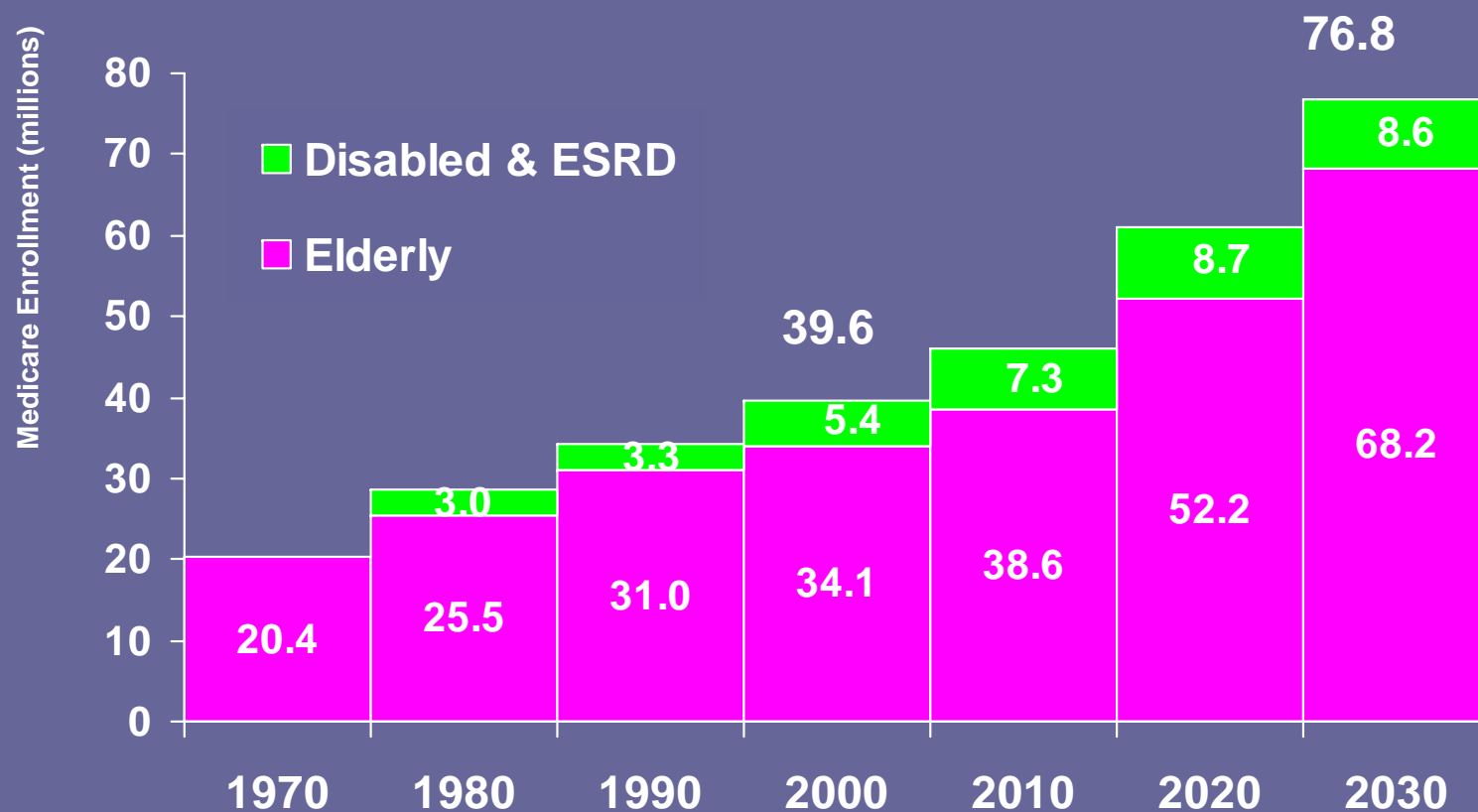
- The SEER-Medicare data reflect the linkage of two large population-based sources of data that provide detailed information about elderly persons with cancer.
- The linkage of these two data sources results in a unique population-based source of information that can be used for an array of epidemiological and health services research.

Surveillance, Epidemiology and End Results (SEER)



Number of Medicare Beneficiaries

The number of people Medicare serves will nearly double by 2030.



Examples of SEER-Medicare Studies of Rare Cancers

- Krzyzanowska MK, et al. Treatment of locally advanced pancreatic cancer in the real world: population-based practices and effectiveness. *J Clin Oncol* 2003;21(18):3409-14.
- Lim JE, et al. Prognostic factors following curative resection for pancreatic adenocarcinoma: a population-based, linked database analysis of 396 patients. *Ann Surg* 2003 Jan;237(1):74-85.
- Urbach DR, et al. Cohort study of surgical bypass to the gallbladder or bile duct for the palliation of jaundice due to pancreatic cancer. *Ann Surg* 2003 Jan;237(1):86-93.
- Sundararajan V, et al. Variations in the use of chemotherapy for elderly patients with advanced ovarian cancer: a population-based study. *J Clin Oncol* 2002 Jan 1;20(1):173-8.
- Hershman D, et al., Effectiveness of platinum-based chemotherapy among elderly patients with advanced ovarian cancer. *Gynecol Oncol* 2004 Aug;94(2):540-9.

Cancer Risk Prediction Models and Rare Cancers

- NCI sponsored “Cancer Risk Prediction Models: a Workshop on Development, Evaluation and Application” on May 20-21 2004 in Washington, DC
- Workshop recommendations for future research included:
 - encouraging the development of risk models for tailoring screening and surveillance efforts and planning chemoprevention trials for melanoma, esophageal, bladder and pancreatic cancer
 - the development of new breast cancer risk models that include subtypes of breast cancer such as DCIS

See: Freedman et al., Cancer Risk Prediction Models: A Workshop on Development, Evaluation, and Application. J Natl Cancer Inst 2005;97:715-23

For Information on Data Access and Research Collaboration

- Breast Cancer Surveillance Consortium(BCSC)
<http://breastscreening.cancer.gov/>
- Cancer Research Network (CRN)
<http://crn.cancer.gov/>
- SEER-Medicare
<http://healthservices.cancer.gov/seermedicare/>